

ACROMEGALY FACT SHEET



What is acromegaly?

Acromegaly is a rare disease that can be challenging to diagnose and treat.^{1,2} It is most frequently caused by a growth hormone (GH)-producing pituitary neuroendocrine tumour (pit-NET), also known as a pituitary adenoma.¹

The incidence of acromegaly varies between 0.2 and 1.1/100,000 individuals per year.¹ Excess GH causes characteristic changes to facial features and affects multiple organ systems. Patients can experience significant burden from the symptoms and complications associated with uncontrolled acromegaly, impairing their quality of life (QoL) and contributing to premature death and a substantial socioeconomic impact.³

With optimal disease management, QoL can be improved, and mortality can be similar to that of the general population.^{2,3}



GH excess can, more rarely, be produced by other tumours such as lymphoma and pancreatic islet cell tumours.⁴



Notable genetic syndromes associated with acromegaly include multiple endocrine neoplasia type 1, familial acromegaly, McCune-Albright syndrome and Carney complex.⁴

Manifestations of acromegaly depend on the progression of the disease.

Clear diagnostic features may not always be present but may involve some aspects shown below.²

Clinical features of acromegaly are the result of excessive GH and insulin-like growth factor 1 (IGF-1) levels, usually noticed by 30–40 years of age:^{2,4}



Tongue enlargement, hyperhidrosis, skin oiliness or thickening³



Weight gain, joint pain, fatigue and headache³

Acral enlargement (thickening of hands and feet) and coarsening of facial features³



Illustration from Dr P. Marazzi / Science Photo Library (M108417)

Illustration from University of Bristol

The majority of patients with acromegaly have comorbidities affecting multiple organ systems:³

respiratory

cardiovascular

metabolic

musculoskeletal

reproductive

gastrointestinal



What to do if you suspect acromegaly in your patient⁵

Measure IGF-1 and fasting GH levels.



If IGF-1 is mildly elevated, **perform an oral glucose tolerance test** to confirm failure of **GH suppression**.



Once biochemical diagnosis is confirmed, **request pituitary magnetic resonance imaging** to identify and characterise the source of GH excess.



Refer promptly to a specialist endocrinologist.

Diagnosis

Biochemical diagnosis can be made based on elevated GH and IGF-1 levels.⁵

Management

Surgical resection of the pituitary tumour is usually performed but may not be sufficient for disease control.^{3,4}

Ongoing biochemical monitoring and systemic treatment such as somatostatin analogues, dopamine receptor agonists or GH-receptor antagonists are frequently required.^{4,6}

The Ipsen Hub has more content which can support you and your patients with acromegaly, including dosing and administration guides, patient support materials, videos and a symptom tracker.

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GH=growth hormone; IGF-1=insulin-like growth factor 1; pit-NET=pituitary neuroendocrine tumour; QoL=quality of life.

1. Pennlund A, et al. *Pituitary*. 2025;28(2):33; 2. Muhammad A, et al. *Neth J Med*. 2015;73(8):362–367; 3. Koobatian M, et al. *J Patient Rep Outcomes*. 2025;9(1):140; 4. Adigun OO, et al. Acromegaly. [Updated 2023 Feb 2]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2026 Jan-. Available from: <https://www.ncbi.nlm.nih.gov/books/NBK431086/> [Last accessed: July 2026]; 5. Fleseriu M, et al. *Lancet Diabetes Endocrinol*. 2022;10(11):804–826; 6. Quock TP, et al. *J Comp Eff Res*. 2025;14(9):e250080.

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